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#### **CHAPTER 4. PERSIAN GULF REFERRAL CENTERS (PGRCs)**

#### 4.01 PURPOSE

This chapter sets forth clinical and administrative policies concerned with program management of Veterans Health Administration (VHA) Persian Gulf Referral Center (PGRC) examination programs established at Department of Veterans Affairs (VA) Medical Centers in Birmingham, AL, Houston, TX, Washington, DC, and West Los Angeles, CA.

#### 4.02 BACKGROUND

- a. In August 1992, VA established three PGRCs to medically assist Persian Gulf veterans whose symptoms defy explanation through the usual diagnostic and therapeutic endeavors of local VA medical centers. An additional center was established in June, 1995. The centers were established when it became clear that increasing number of Desert Storm veterans appeared to be incapacitated and had symptoms which eluded routine medical diagnosis despite thorough medical work-ups at VA medical centers. VA determined that for these veterans it was desirable to provide for inpatient stays to allow for observation, multidisciplinary consultation, documentation of lengthy occupational and exposure histories, and an opportunity for frequent re-examination. For such veterans, local VA medical centers make special arrangements for the transfer, following consultation with the referral center clinicians, to the appropriate center.
- b. The referral centers, located at VA Medical Center in Birmingham, AL, Houston, TX, Washington, DC, and West Los Angeles, CA, were selected based on availability of clinical and academic expertise in such areas as pulmonary and infectious diseases, neurology, immunology, neuropsychology and access to toxicologic expertise. The centers place an emphasis on specific symptom complexes, such as fevers of unknown origin, chronic fatigue, memory loss, unexplained weight loss and other adverse health conditions possibly associated with chemical/toxic environmental exposures in the Persian Gulf.

#### 4.03 AUTHORITY

Authority for the VHA PGRCs is provided by Persian Gulf-related legislation including:

- a. Public Law (Pub. L.) 102-25 which established a Persian Gulf War period of service affecting persons serving on active duty as of August 2, 1990. At this time, there is no ending date established by law.
- b. Pub. L. 102-585, Title VII, "Persian Gulf War Veterans' Health Status Act," enacted November 4, 1992, mandates the Secretary of Veterans Affairs to establish and maintain a Persian Gulf Registry and provide health examinations and counseling for eligible veterans;
- c. Pub. L. 103-210, enacted December 20, 1993, provides the Secretary of Veterans Affairs, with authority to provide priority health care for eligible Persian Gulf veterans presenting adverse health conditions possibly associated with service in the Persian Gulf.

#### 4.04 POLICY

Persian Gulf veterans already determined to be eligible for a Persian Gulf Registry examination and/or health care under the authorities cited in paragraphs 2.02 and 3.02, and who have been admitted for outpatient and/or inpatient care at a VA medical center, may be considered for referral to a PGRC **NOTE**: *Final eligibility determinations for admission to a PGRC is be left to the discretion of the PGRC Director*.

#### 4.05 PROGRAM GUIDANCE

a. Special directives and other program guidance prepared by VA Central Office's Environmental Agents Service (EAS) (103A), provides the basis for PGRC program activities.

b. Appropriate means, i.e., medical center memoranda, need to be taken to circulate this information throughout each Referral Center.

- c. PGRC staff must be aware of educational information and other materials and publications prepared by EAS (e.g., Persian Gulf posters, Persian Gulf Reviews, Persian Gulf Staff Updates, Persian Gulf Fact Sheets, etc.).
- d. It is expected that PGRC staff will participate in national education meetings and attend periodic nationwide conference calls conducted by the EAS. **NOTE**: They should be joined by VA medical center staff concerned with the delivery of health care to Persian Gulf veterans and the maintenance of the Persian Gulf Registry Examination Program.

#### 4.06 RESPONSIBILITIES

- a. PGRC program management requires close coordination and interaction between PGRC staff and VA medical center staff making medical referrals of Persian Gulf veterans with difficult to diagnose health conditions.
- b. VA Central Office's EAS (103A) provides program guidance and administratively oversee activities of the PGRCs and referring medical centers.
- c. <u>PGRC Responsibilities</u>. A specially dedicated clinical and administrative support staff headed by a "Referral Center Clinical Director" is established at each PGRC. The Director is responsible for the clinical management of all medical and administrative activities associated with the special diagnostic program. Major responsibilities include:
- (1) Consulting with VA medical center staff to determine appropriateness of referral of Persian Gulf veteran to the PGRC.
- (2) Providing medical consultation to VA medical centers of origin for those cases in which it is determined that a PGRC admission is not required. Such consultative support is to assist the local medical center in arriving at a diagnosis and treatment regimen for Persian gulf veteran(s) in question.
- (3) Providing for all administrative aspects of admission, with the close support and assistance of the medical center's Medical Administration Service (MAS), of patient referrals to the PGRC.
  - (4) Developing a medical plan of action on each referral, i.e.:
  - (a) Reviewing and confirming the complete medical history in veteran's Consolidated Health Record (CHR).
  - (b) Providing a comprehensive physical examination,
  - (c) Providing routine baseline laboratory tests,
  - (d) Providing other diagnostic testing as required, and
  - (e) Arranging specialty consultations as determined medically appropriate.
- (5) Advising the veteran(s) if they have not already done so, of the opportunity to participate in, and be included in VA's computerized Persian Gulf Veterans Health Registry Examination Program. If veteran wishes to participate in the registry, the PGRC is to ensure compliance with all registry procedures as outlined in M-10, Part III, Chapter 2. **NOTE**: Before referral to one of VA's PGRCs, it is requested that all VA medical centers perform a Persian Gulf Registry Examination (Phase I) and if at all possible a Uniform Case Assessment Protocol (UCAP) (Phase II).
- (6) Providing for the documentation in the veteran's CHR of all medical information pertinent to each referral (PGR code sheets, laboratory reports, etc.).

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(7) Upon conclusion of the PGRC's diagnostic work-up of each veteran, providing for administrative referral of that individual back to the referring medical center. The PGRC contacts the medical center of referral prior to the veteran's departure from the facility.

- (8) Providing each veteran with a final "consultation" by the PGRC Director, and/or other PGRC staff as designated, of results of diagnostic procedures/treatment.
- (9) Providing each referral with a follow-up letter discussing the results of the diagnostic work-up at the PGRC including results of examination and laboratory tests with recommendations, as appropriate, personalized to each referral.
- (10) Providing copies of pending test or consultation results for each referred veteran to EAS (103A) and VA facility of origin.
- (11) Completing a VA Form 10-9009A (July 1995), Persian Gulf Registry Code Sheet, and sending to Austin Automation Center (AAC) as a follow-up examination when there is a new diagnosis or a change in diagnosis since the initial registry examination code sheet should have been completed by the referral facility and sent to AAC as an initial examination.
  - (12) Maintaining a special file on each referral at PGRC, for easy accessibility.
- (13) Providing cumulative monthly reports to EAS (103A) no later than 5 working days following the end of each month, see paragraph 3.05 and Appendix 3B.
- (14) Providing copies of discharge summaries, laboratory test results and code sheets (both initial examination and follow-up, if there is a new diagnosis or a change in diagnosis, for each referred Persian Gulf veteran, to EAS (103A) within 5 working days following the end of each monthly reporting period (see par. 3.05 and App. 3B).
- d. <u>Originating Medical Center Responsibilities</u>. VA medical centers are responsible for the medical referral to the PGRCs of those Persian Gulf veterans for whom a medical diagnosis cannot reasonably be determined in spite of extensive diagnostic, including comprehensive clinical examination work-ups. Routine responsibilities of the medical centers making the referral are:
- (1) Contacting the Director, PGRC, or other appropriate PGRC clinical staff member to discuss patients who meet the necessary criteria for referral. Referral criteria include:
- (a) Performing a Persian Gulf Registry examination, Phase I and Phase II (if facility has these medical capabilities), prior to referral consideration; and
- (b) Reviewing medical records of those Persian Gulf veterans with multiple symptoms for which a diagnosis has not been determined or those veterans requiring a "second opinion."
- (2) Providing, when necessary, the appropriate PGRC with any documentation which will assist the PGRC in making its determination whether a referral is appropriate, i.e., any examination data described in the patient's CHR including, among others, medical history, progress notes, test results, Persian Gulf Registry diagnostic code sheets, and any other relevant medical/demographic information.
- (3) Coordinating with the PGRC clinical and medical administrative service staff, all necessary travel and per diem arrangements for the veteran(s), including dates of planned transfer to the referral center and projected return date.
- (4) Obtaining the veteran's permission for transfer and providing counseling concerning the reason(s) for referral, projected period of inpatient admission at the PGRC, travel arrangements and responding to any questions the veteran might have concerning the referral. **NOTE:** *In some instances veterans may not wish to be referred. Ensure that documentation of the veteran's decision in this regard is fully documented in the CHR progress notes.*

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- (5) Upon notification of a referral's return from the PGRC, initiating follow-up contact by telephone and/or letter with the veteran within 2 weeks of discharge from the referral center to determine the veteran's health status and to provide any assistance for which the veteran may be eligible.
- (6) Discussing with Referral Center Directors outstanding consultation results, either performed at referral centers or to be completed at the local medical centers, and maintained in patient's files at both facilities (local and referral).
- (7) Documenting within the veteran's CHR all results, findings and recommendations of the special diagnostic work-up provided by the PGRC.

#### 4.07 REPORTING REQUIREMENTS

- a. Originating VA medical centers
- (1) Prepare an original VA Form 10-9009A (July 1995) for each referred Persian Gulf Registry veteran.
- (2) Submit a legible copy to the ACC in accordance with the general instructions found in Appendix 2C.
- (3) Submit a legible copy of the VA Form 10-9009A (July 1995) to the PGRC with the patients CHR.
- (4) Submit all follow-up results of specialty consultations obtained after the veteran's discharge from a PGRC, including further consultation with the veteran, if appropriate, to:

Department of Veterans Affairs EAS (103) ATTN: Senior Registry Coordinator 810 Vermont Avenue, N.W. Washington, DC 20420

#### b. PGRC

- (1) Submit follow-up Persian Gulf Code Sheets (VA Form 10-9009A (July 1995)) to AAC when new diagnostic code differs from previously submitted code sheets, (see App.2B).
- (2). Submit a PGRC report of admissions and/or discharges to EAS (103A), Attn.: Senior Registry Coordinator, within 5 working days following the end of each reporting month (refer to App. 2B for instructions and sample format).
  - (3) Submit a negative PGRC report if there were no admissions or discharges during the reporting month.
- (4) Submit copies of discharge summaries, laboratory reports, i.e., chest x-ray, blood count, blood chemistries or enzyme studies, urinalysis and code sheets to EAS (103A), Attn.: Senior Registry Coordinator, no later than 10 working days following the end of each month.
  - (5) Submit all original medical records to local VA medical center to be maintained in veteran's CHR.
  - (6) Maintain copies at PGRC in a special file for each referred patient.
- (7) Submit copies of results of follow-up specialty consultation after discharge of veteran from PGRC to EAS and local VA medical center for patient's CHR and/or further consultation with veteran, if appropriate.

## 4.08 MEDIA AND OTHER EXTERNAL CONTACTS

a. **Media Contacts.** Reports of Contact from various media sources (e.g., radio, television, newspapers, etc.) concerning PGRC activities will be referred by phone to the facility public affairs officer. Interviews should not be

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given unless approved by the medical center Public Affairs Officer who may appropriately coordinate response with the regional VA public affairs representative.

- b. Contacts to Advise Centers of "Special Cures" for Persian Gulf-related Illnesses. Referral centers can expect, on occasion, to be contacted by private sector physicians, researchers, and the general public with information regarding "quick cures" for Persian Gulf-related illnesses. Such individuals need to be politely advised that:
  - (1) There are medically accepted mechanisms to introduce new clinical treatments.
- (2) All new treatments suggested must be reviewed by a formally designated and staffed human subjects review committee.
  - (3) It is important to have independent confirmation of treatment efficacy.
- (4) Provisions exist to permit the originator of new therapies to retain professional credit and be appropriately compensated.
- (5) The individual might want to consider presenting the "new approach" at a VA or medical school grand rounds or staff review committee meetings.
  - (6) VA and the National Institutes of Health fund quality research proposals.

# INSTRUCTIONS AND SAMPLE FORMAT FOR COMPLETION OF PERSIAN GULF REFERRAL CENTER MONTHLY REPORT (RCS 10-0860)

A monthly report is required from all Department of Veterans Affairs (VA) Persian Gulf Referral Centers (PGRC) receiving an extensive, additional diagnostic and therapeutic work-up to evaluate those Persian Gulf War veterans who are incapacitated and experiencing symptoms that have eluded medical diagnosis despite thorough examinations at local VA facilities. The following instructions are provided for the completion and submission of this reported **NOTE**: A sample report is provide on page 4A-2.

- 1. Title of Report. Monthly Persian Gulf Referral Center Report
- 2. Reporting Period. Month and Year of the reporting period.
- 3. **Reporting Facility, Address and Station Code.** Identify name, address and station code of each reporting PGRC.
- 4. **Column A.** Include the Persian Gulf veteran's name, Social Security Number, Race, Sex and Branch of Service.
- 5. **Column B.** Provide the name, city and state of the VA facility from which the Persian Gulf veteran was referred.
- 6. **Column C.** Indicate date of admission, date of discharge, and the date of initial Persian Gulf Registry examination.
- 7. **Column D.** List up to ten exposures as indicated by the veteran.
- 8. Column E. List up to ten symptoms/complaints (with ICD-9 codes) as indicated by the veteran.
- 9. Column F. List up to ten diagnoses (with ICD-9 codes). If there are no diagnoses, -indicate "None."
- 10. **Column G.** List all pending tests/consultations/procedures, either those that have been performed at the PGRC or those to be performed at the local VA medical center.
- 11. **Number of Veterans.** List the total number of Persian Gulf veterans admitted, discharged and any pending referrals for current reporting month and cumulative numbers from the onset of this program:
  - a. Total Admissions;
  - b. Total Discharges; and
  - c. Total Referrals Pending: (current month).
- 12. **Date of Report.** Submit the date of this report.
- 13. Contact. Name of staff member preparing this report and the telephone contact.
- 14. **Mailing Address**. This report must be transmitted to the following address:

Department of Veterans Affairs Environmental Agents Service (103A) ATTN: Persian Gulf Coordinator 810 Vermont Avenue, N.W. Washington, DC 20420 PERSIAN GULF REFERRAL CENTER MONTHLY REPORT (RCS 10-0860) REPORTING MONTH JULY, 1994 PGRC: HOUSTON, TX (580)

(A)	(B)	(C)	(D)	(E)	(F)	(G)
NAME/SSN/ AGE/RACE/SEX BRANCH OF SERVICE	REFERRED BY: VAMC/OPC	ADMISSION/ DISCHARG E PGR EXAM DATES	LIST OF EXPOSURES (UP TO TEN)	LIST OF SYMPTOMS (UP TO TEN)& ICD-9 CODES	LIST OF DIAGNOSIS (UP TO TEN) & ICD-9 CODES	PENDING TESTS/CON- SULTATIONS/ PROCEDURES
JONES,HARRY 555-55-5555 40 Y.O.W.M. ARMY	ALBANY, NY VAMC	5/1/94 5/10/94 4/11/93	DU; CARC; PESTICIDES	FATIGUE/ MALAISE (7807)	NEURA- STHENIA (3005)	MRI; THYROID FUNCTION TEST
SMITH,JOHN 333-33-3333 25 Y.O.B.M.* NAVY	MONTROSE, NY VAMC	5/2/94 5/19/94; 3/10/94.	OIL FIRE SMOKE; ANTHRAX VACCINE.	JOINT PAIN (78999); MEMORY LOSS (7809); LOOSE BOWEL STOOLS (7879); FATIGUE (7807); HEARING LOSS (78999); HEADACHES (7840);	MULTIPLE SYMPTOMS OF UNKNOWN ETIOLOGY (7999)	NEURO- PSYCHO- LOGICAL
WRIGHT, ANN 666-66-6666 30 Y.O.W.F.** ARMY	DURHAM VAMC	5/20/94; 5/30/94; 3/4/94.	TENT HEATER SMOKE; ATE LOCAL FOOD; MICROWAVES.	FATIGUE (7807); JOINT PAINS (78999); HEADACHES (7840); SLEEPLESSNESS (78050); LOOSE BOWEL STOOLS (7879)	ARTHRALGIA (7194); DIARRHEA (3064)	NONE

### SUMMARIES

	ADMISSIONS	DISCHARGES:	PENDING EXAMS:
CURRENT MO.	3	3	10
CUMULATIVE:	10	10	N/A

DATE: 8/7/94;

PREPARED BY: JOHN DOE; PHONE #713-222-222
\*-Y.O.B.M. (Year Old Black Male)
\*\*-Y.O.W.F. (Year Old White Female)